
CANCER FACTS

National Cancer Institute • National Institutes of Health

Questions and Answers About Care for Children and Adolescents with Cancer

Survival rates for childhood cancer have risen sharply over the past 20 years. In the United States, more than 75 percent of children with cancer are now alive 5 years after diagnosis, compared with about 60 percent in the mid-1970s. Much of this dramatic improvement is due to the development of improved therapies at children's cancer centers, where the majority of children with cancer have their treatment.

1. What are children's cancer centers?

Children's cancer centers are hospitals or units in hospitals that specialize in the diagnosis and treatment of cancer in children and adolescents. Most children's, or pediatric, cancer centers treat patients up to the age of 20.

2. Are there standards for children's cancer centers?

The following groups have established standards for children's cancer centers or programs:

- The National Cancer Institute (NCI)-sponsored Children's Oncology Group (COG), formerly known as the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG), is a network of children's cancer centers that meet strict quality assurance standards.
- The American Academy of Pediatrics (AAP) published Guidelines for the Pediatric Cancer Center and Role of such Centers in Diagnosis and Treatment in 1986 and 1997.
- The American Society of Pediatric Hematology/Oncology (ASPH/O) established standard requirements for programs treating children with cancer and blood disorders.

These groups agree that a childhood cancer center should be staffed by trained pediatric oncologists (doctors who specialize in childhood cancer) and other specialists who work as a team. Other members of the health professional team usually include pediatric

surgeons, specialist surgeons (for instance neurosurgeons and urologic surgeons), radiation oncologists, pathologists, nurses, consulting pediatric specialists, psychiatrists, oncology social workers, nutritionists, and home health care professionals—all with expertise in treating children and adolescents with cancer. Together, these professionals offer comprehensive care.

3. Why might a family look for a specialized children’s cancer center when a child or adolescent is diagnosed with cancer?

Because childhood cancer is relatively rare, it is important to seek treatment in centers that specialize in the treatment of children with cancer. Specialized cancer programs at comprehensive, multidisciplinary cancer centers follow established protocols (step-by-step guidelines for treatment). These protocols are carried out using a team approach. The team of health professionals is involved in designing the appropriate treatment and support program for the child and the child’s family. In addition, these centers participate in specially designed and monitored research studies that help develop more effective treatments and address issues of long-term childhood cancer survival.

4. When children go to a specialized cancer center, does it mean their treatment will be part of a research study?

Not necessarily. Participation in research studies is always voluntary. Parents and patients may choose to receive treatment as part of a clinical trial (research study); only patients and parents who wish to do so take part. However, a large number of children who go to pediatric cancer centers take part in clinical trials. About two-thirds of children with cancer are treated in a clinical trial at some point during their illness.

5. What is a clinical trial or research study?

In cancer research, a clinical trial is a study designed to show how a particular strategy—for instance, a promising anticancer drug, a new diagnostic test, or a possible way to prevent cancer—affects the people who receive it.

Treatment clinical studies fall into three categories:

- Phase I studies test the safety and determine the dose of a new treatment in a small number of patients.
- Phase II studies check how effective a treatment is against different kinds of cancer.
- Phase III studies, which usually involve many patients in different places, generally compare two or more different treatments.

6. What are the benefits of taking part in a clinical trial?

One advantage is the possibility that a new treatment (or diagnostic test or preventive measure) will turn out to be better than a more established method. Patients who take part in approaches that prove to be better have the first chance to benefit from them. In phase III clinical trials, in which one treatment is compared with another, patients receive either the most advanced and accepted treatment for the kind of cancer they have—known as the "standard" treatment—or a new treatment that has shown promise of being at least as beneficial as the standard treatment.

People who take part in clinical trials receive specialized care under a very precise set of directions, or protocol. To ensure quality care, highly trained and experienced cancer specialists design, review, and approve each protocol. In addition, all participants in clinical trials are carefully monitored during the study and are followed afterwards. Participants are often included in a network of clinical trials carried out around the country. In this network, doctors and researchers share their ideas and experience, and patients receive the benefit of the shared knowledge.

7. What are the risks of taking part in a clinical trial?

Clinical trials can involve risks as well as benefits. All cancer treatments have side effects, but treatments being studied may have side effects that are not yet understood as well as the side effects of standard treatments. The potential risks and benefits of each study are explained during the informed consent process. This means that patients and families discuss all aspects of the study with their doctors or nurses before deciding whether to participate.

8. What about costs? Do insurance or managed care plans cover treatment at a children's cancer center?

Some health plans cover part or all of the cost of care at children's cancer centers, but benefits vary from plan to plan. Questions or concerns about health care costs should be discussed with a medical social worker or the hospital or clinic billing office. Financial assistance and resources to cover health care costs may be available.

9. Can children with cancer be treated at the National Cancer Institute?

The Pediatric Oncology Branch (POB) of the National Cancer Institute conducts clinical trials for a wide variety of childhood cancers at the Warren Grant Magnuson Clinical Center, which is located at the National Institutes of Health in Bethesda, Maryland. There is no charge to patients for services provided at the Clinical Center.

Children, teenagers, and young adults with newly diagnosed or recurrent cancer (cancer that has come back) may be referred to the POB. To refer a patient with cancer, the patient's doctor should call the POB's toll-free number at 1-877-624-4878 between the

hours of 8:30 a.m. and 5:00 p.m. and ask for the attending physician. The attending physician will discuss the case with the patient's doctor, determine whether the patient is eligible for treatment at NCI, and help arrange the referral. The POB can also be reached at <http://www-dcs.nci.nih.gov/branches/pedonc/index.html> on the Internet.

POB attending physicians also are available to provide a second opinion about a patient. The patient, family, or physician can contact the POB to arrange for a second opinion. POB staff can offer assistance in cases where a diagnosis is difficult and also can aid in developing an appropriate treatment plan.

10. How does a family find a children's cancer center?

A family's pediatrician or family doctor often can provide a referral to a comprehensive children's cancer center. Families and health professionals also can call the NCI's Cancer Information Service (CIS) at 1-800-4-CANCER to learn about children's cancer centers that belong to the Children's Cancer Study Group and the Pediatric Oncology Group. All of the cancer centers that participate in these Groups have met strict standards of excellence for childhood cancer care.

11. How do families cope with practical issues like getting to a center and finding a place to stay near the center?

Many families receive helpful information from their doctors, nurses, or social workers. In addition, various organizations offer support to families, including help with transportation, lodging, and financial assistance. Sources of help include:

The Candlelighters Childhood Cancer Foundation. Candlelighters is an international organization of parents whose children have or have had cancer. It offers information and assistance to families through a national parent information service, newsletters, and other publications. It also has local chapters in many towns and cities around the United States, which can be important sources of practical information and support for families.

Address:	The Candlelighters Childhood Cancer Foundation 3910 Warner Street Kensington, MD 20895
Telephone:	301-962-3520 or 1-800-366-CCCF (1-800-366-2223)
Fax:	301-962-3521
E-mail:	info@candlelighters.org
Internet Web site:	http://www.candlelighters.org

The Leukemia and Lymphoma Society. Financial assistance and consultation services for referrals to other means of local support are offered by chapters of the

Leukemia and Lymphoma Society to patients with leukemia, lymphomas, and myeloma. Educational materials for patients and family members are provided through local chapters and the Home Office.

Address: The Leukemia and Lymphoma Society
1311 Mamaroneck Avenue
White Plains, NY 10605-5221
Telephone: 1-800-955-4LSA (1-800-955-4572)
E-mail: infocenter@leukemia-lymphoma.org
Internet Web site: <http://www.leukemia-lymphoma.org>

Ronald McDonald House Charities. Many major cities have Ronald McDonald Houses where out-of-town families can stay while their children are being treated for a serious illness. The room rates are economical. A social worker may be able to help locate one, or contact the Ronald McDonald House Coordinator at the address below.

Address: Ronald McDonald House Charities
One Kroc Drive
Oak Brook, IL 60523
Telephone: 630-623-7048
Internet Web site: <http://www.rmhc.com/about/programs/education/rmh>

The National Children's Cancer Society. This independent, national organization provides a broad range of services, including financial and in-kind assistance, advocacy, support services, and education and prevention programs.

Address: National Children's Cancer Society
Suite 600
1015 Locust Street
St. Louis, MO 63101
Telephone: 1-800-5-FAMILY (1-800-532-6459)
Internet Web site: <http://www.children-cancer.com>

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Sources of National Cancer Institute Information

Cancer Information Service

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY (for deaf and hard of hearing callers): 1-800-332-8615

NCI Online***Internet***

Use <http://cancer.gov> to reach NCI's Web site.

CancerMail Service

To obtain a contents list, send e-mail to cancermail@icicc.nci.nih.gov with the word "help" in the body of the message.

CancerFax® fax on demand service

Dial 301-402-5874 or 1-800-624-2511 and listen to recorded instructions.

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